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The reported expression of pain and distress by people with an intellectual disability

ABSTRACT

Background: The healthcare needs of people with an intellectual disability (ID) may often be overlooked or dealt with inappropriately. It has been suggested that one reason may be the difficulty that such individuals have in communicating about their pain.

Aims and objectives: The study aimed to explore the assumption that people with ID are unable to communicate effectively about pain by examining the extent to which they were reported as using language and behaviour that was readily understandable to others to communicate pain as distinct from distress.

Design: A postal questionnaire based mixed method design was used.

Method: The data from carer reports (n=29) of the ways the people with ID they supported expressed pain and distress were categorised and analysed using descriptive statistics and thematic content analysis

Results: Of the 22 people who used verbal communication, 19 (86%) were reported to express pain using words that would be understandable to someone else, often accompanied by behavioural indications of the location of the pain. The language and behaviour that was reported as being used to express distress was more idiosyncratic and there was little overlap between this and the ways in which pain was expressed.

Conclusion: The results provide some challenges to the view that people with ID are necessarily unable to communicate effectively about their pain and support the view that pain and distress can be conceptually distinguished and differentially communicated by some people with ID.

Relevance to clinical practice: The results suggest that many people with ID can be active participants in describing their experience of pain and that nurses should attempt to obtain this information directly from the individual during the diagnostic process. In addition, nurses need to be mindful of the distinction between pain and distress and should not respond to signs of distress in this group as being indicative of pain, without carrying out further assessment.

Keywords: Pain, Distress, Language, Intellectual Disabilities, Postal Survey

Word count: 4854

INTRODUCTION

It has been suggested that a significant barrier to identifying the health care needs of people with an intellectual disability is the difficulty that such individuals may have in expressing pain (Foley & McCutcheon 2004). A key part of diagnosis and treatment in this area is the ability to identify the presence, location and type of pain that is being experienced by the patient (Dodd 1999, Foley & McCutcheon 2004). This often relies heavily on patients being able to communicate effectively to the healthcare professional that they are in pain, as well as the nature and location of the pain. As well as aiding with diagnosis and signposting appropriate interventions, pain can also serve to provide an indicator of the success or otherwise of treatment and help identify factors that have a relationship with the pain (Bromley et al. 1998). Without this information, the diagnosis and treatment of underlying health conditions that are causing the pain are more difficult.

As a result of community care policies, the majority of people with an intellectual disability now live in community settings and have their health care needs met by primary care services (Department of Health 2001). Policy documents in the UK have emphasised, that while specialist intellectual disability services should act as health facilitators, meeting the health care needs of people with an intellectual disability is the responsibility of all nurses and that the profession as a whole has a remit to promote better health in this group (e.g., Scottish Executive 2002). This highlights the need for nurses in a range of healthcare settings, from primary care practices to accident and emergency departments, to be able to communicate effectively with people with an intellectual disability in order to understand their pain experience.

This is particularly important as research has indicated that people with an intellectual disability commonly experience pain (e.g., Breau et al. 2003, 2007) but that it is not always recognised. As well as the implications this has for diagnosis and treatment, as outlined above, and the obvious inherent unpleasant nature of the pain itself, it also has a wider impact on the quality of life of the individual. A case study of chronic pain management in people with intellectual disability reports that pain-related fear and fear of movement can disable people more than the pain itself (Lewis et al. 2007). Taking a broader view, Breau et al. (2007) found that on days when individuals with an intellectual disability experienced pain, they also engaged in fewer adaptive activities. This was not restricted to activities which might have resulted in worse pain e.g. increased physical activity, but rather was found across all four of the areas measured: communication, daily living skills, socialisation and motor skills. As people with an intellectual disability, by definition, already have significant impairments in their adaptive functioning, this further reduction in adaptive activity represents an additional potentially serious side effect of the failure to recognise pain in this group.

BACKGROUND

There are a number of reasons why pain in people with an intellectual disability may not be readily identified. It is recognised that pain is a subjective phenomenon which is influenced by a number of factors, including past experience of pain, culture, expectations, and the context in which the person experiences the pain (Smith 1998,

Bourbonnais et al. 2004). This emphasises the complexity of the pain pathway for each individual and the roles which mediating factors can play in the pain experience. One important mediating factor is the interpretation that others make of indicators of pain. Accessing appropriate health care may depend on parents or carers picking up and correctly interpreting indicators from people with an intellectual disability that they are in pain (Foley & McCutcheon 2004, Beacroft & Dodd, 2010). However, beliefs, such that this group have a higher pain threshold than the general population (Beacroft & Dodd 2009), despite evidence that this generalisation does not apply to all people with an intellectual disability (Biersdorff 1994) may mean that signals are missed, misinterpreted or wrongly attributed to a cause other than pain (Kerr et al. 2006, Clarke et al. 2007). For example, Kerr et al. (2006) found that as people with intellectual disability are, for various reasons, more likely to display behaviour that challenges (such as aggression or self-harm) than some other groups, staff may not initially consider disruptive behaviour as a response to pain.

Research has also indicated that others are inclined to identify pain on the basis of behavioural cues (Zwakhalen et al. 2003, Clarke et al. 2007, Regnard et al. 2007), rather than on the basis of what the person says about pain, and Zwakhalen et al. (2003) argue that the ‘gold standard’ of assessing pain i.e. self-report can’t be used with this group of people. Indeed, there is a body of research suggesting that people with an intellectual disability may not have the communication abilities to express when they are in pain or the nature of the pain they are experiencing (Regnard et al. 2007, Beacroft & Dodd 2009, 2011). As a result, many pain assessments for use by health care professionals have been developed on the basis of behavioural indicators (e.g., McGrath et al. 1998, Breau et al. 2002, Zwakhalen et al. 2003).

This work has led to an increased understanding about what some candidate behavioural indicators of pain might be in those who lack the communication skills to express these verbally. However, as Symons et al. (2008) note, a difficulty with this work is that there may be a number of different causes that result in the same behaviour. Regnard et al. (2007) therefore, make the point that these candidate behaviours should be viewed as indicators of distress rather than pain. The authors note that this distinction is important because research suggests that there are no universal indicators of pain (Regnard et al. 2003) and that distress may be due to causes other than pain. As they note that ‘distress’ has no “common meaning among carers” (2007, p277), they take it as a generalised indicator of discontent, or altered state.

This emphasis on behavioural indicators of pain and the question of differentiating it from distress is understandable, given the importance of identifying and alleviating pain in those who are unable to express it directly. It has, however, resulted in a relative neglect of research looking at the extent to which people with an intellectual disability can communicate pain verbally, using language that is commonly understood to indicate pain. Early research in this area suggested, perhaps unsurprisingly, that those with greater cognitive impairment had greater difficulty in communicating the intensity of their pain (Biersdorff 1994) and that while people with less intellectual impairment could self-report pain, they were not always accurate when localising the source of their pain (Hennequin 2000).

Bromley et al. (1998) used photographs which depicted painful experiences to compare the ability of people with and without an intellectual disability to identify the intensity and location of the pain. They found that: in most comparisons there were no differences between the groups on locating the pain; that people with an intellectual disability were more likely to rate the pain depicted as more intense, and that the judgements of the people with an intellectual disability were relatively stable over time. Interestingly, the ability on this task was found to be unrelated to cognitive ability. While the numbers in the study were small and the task was not a self-report one, it does suggest that people with an intellectual disability can describe pain intensity and location with some accuracy and reliability.

A more recent study was conducted by Beacroft and Dodd (2011), in which they interviewed 40 people with an intellectual disability about their pain experiences. The majority were described as having a mild intellectual disability (73%), with the remainder having a moderate intellectual disability. The authors found that most people could identify common body parts, but had more difficulty with internal organs e.g. kidneys. When asked ‘what is pain?’ participants used commonly understood words e.g. ‘painful’ ‘it hurts’ but had difficulty describing types of pain. This is hardly surprising given that the resistance of pain to language has been taken as central to pain experience (Scarry 1985, Smith 1998). Scarry goes so far as to write that “physical pain ... actively destroys it [language]” (1985, p4). In this difficult area of communication, Beacroft and Dodd (2011) go some way towards indicating the language used by people with an intellectual disability when talking about pain as a topic. The present study aims to build on this work by exploring the vocabulary actually used by people with an intellectual disability to express their own

pain and whether they use pain language similar to that recognisable as such by the general population (Melzack 1979). In addition, following the distinction made by Regnard et al. (2007) between pain and distress, the study also explores the language used to describe the latter.

Pain and distress

Although the terms ‘pain’ and ‘distress’ are used in different ways and fulfil different communicative purposes in everyday language, conceptually they are linked. Pain is usually taken first and foremost to refer to bodily suffering, but it can also refer to mental suffering. The International Society for the Study of Pain’s much quoted definition highlights the psychological nature of bodily suffering, and avoids tying it to a stimulus: pain is “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (Merskey and IASP Subcommittee on Taxonomy 1979, p250). This encompasses the importance of wider aspects of emotion, experience, language and culture (Smith 1998).

Distress, therefore, is intimately implicated in pain of all kinds. Taking distress as a starting point does not facilitate disambiguation as, for example, ‘distress’ is defined by Chambers English Dictionary (1988, p413) as: “extreme pain or suffering: that which causes suffering...”. As a concept, ‘distress’ has received less health-related attention than ‘pain’, but is generally taken to refer to the emotions, and to relate first and foremost to social situations, personal relations, and contexts. Therefore, for the purposes of this research we are defining ‘pain’ as a psychological occurrence involving suffering but generated by the experience of a noxious bodily episode.

‘Distress’ is an emotional state involving suffering but unrelated to a bodily noxious event. The design of the questionnaire used in this research relied on ‘first and foremost’ understandings of the two terms, supported by examples of what we mean by ‘distress’.

METHOD

Ethical approval

Approval for the study was obtained from the authors’ educational institution.

Design

A postal questionnaire was used to obtain reports from paid carers about how the people they supported expressed pain and distress. Following obtaining ethical approval for the study, information letters and questionnaires were sent to service managers of community based support services for people with an intellectual disability in an area in Southern Scotland. The managers were requested to distribute these to frontline staff within their services. Consent to participate was assumed if the questionnaire was returned. One hundred questionnaires were distributed and 29 were returned, giving a response rate of 29%. This is similar to rates found in previous research using postal surveys (Harrison & Cock 2004).

Participants

Inclusion and exclusion criteria

Participants were included if they were a carer and had supported a person with an intellectual disability who lived independently or in shared accommodation in the community for more than one month. This period was chosen on the basis that people

with an intellectual disability commonly experience pain (Breau et al. 2003, 2007). Participants were excluded if they did not have the literacy skills to complete the questionnaire.

Twenty nine people participated. Of these 11 were males and 15 females (data were missing for 3 people). Ages ranged from 20 to 64 (mean = 46.5, sd= 9.6). The time they had supported the individual with an intellectual disability ranged from 6 weeks to 14 years (mean = 5.1, sd =3.1). Information about the people they supported is given in the results section.

Measure

A questionnaire was specifically designed for the study (see appendix 1). It asked the following:

1. Demographic information about the respondent and the individual he/she supported including gender and (for the latter) level of intellectual disability if known and whether the person had current or past medical problems or injuries
2. How the person with an intellectual disability communicated (both in terms of what the person did and said) that he/she is:
 - in pain
 - distressed

The questionnaire was designed as a means of gathering information in a structured way, rather than as a psychometric tool. As such, it was only possible to assess the face, content and social validity and inter-rater reliability of the questionnaire. Content validity, i.e. the subjective judgement that the items are representative of the content area (Eby 1993) of the questionnaire was established by ensuring the questions took account of previous research, for example the importance of distinguishing between pain and distress (Regnard et al. 2007) and the fact that pain and distress can be communicated through behaviour as well as verbally (e.g. Zwakhalen et al. 2003).

Face validity i.e. the extent to which the questionnaire seems to be measuring what it claims to be (Eby 1993) was established by piloting the original questionnaire with 6 social care staff (5 females, 1 male), a Speech and Language Therapist and a Clinical Psychologist, all of whom worked with people with an intellectual disability. All respondents concluded that the questionnaire had face validity. One respondent suggested that it would be helpful to provide examples of what was meant by 'distress' and on the basis of this, examples were added to the final questionnaire (e.g. upset, afraid, and worried). No other suggested changes were received at the pilot stage and the respondents indicated that the questionnaire was easy to understand and use.

Social validity i.e. the extent to which the measure covers areas of relevance to the group it is being applied to (Stanley & Roy 1988) was established by the fact that all of the items were derived directly from areas which were identified in previous

research as being important in the study of pain in people with an intellectual disability.

It was not possible to establish the criterion related validity (the relationship between the questionnaire and an existing validated measure) because of a lack of established measures of pain and distress for people with an intellectual disability, against which to compare the questionnaire used in the present study. Similarly construct validity (the extent to which the questionnaire reflected the theoretical concept in question) was not applicable to the measure used in the present study.

The inter-rater reliability of the questionnaire i.e. the extent to which two or more raters agree (Crookes & Davis 1998), was established by having two raters independently code the data into themes. An agreement rate of 87% was found in relation to the classification of the themes.

Data Analysis

Thematic analysis was used to analyse the data, with the main themes being extrapolated from participant responses. These were reviewed by an independent coder in order to obtain inter-rater reliability, as noted above.

RESULTS

Descriptive Statistics

Demographics of the people with an intellectual disability.

There were 18 males and 11 females in the sample and ages ranged from 23 to 81 (mean = 49.9, sd = 18.4). Reported level of intellectual disability was 'mild' for 4, 'moderate' for 6, 'severe' for 8 and 'profound' for 6. The remaining data were missing. Eighteen people were reported as having a current medical problem or injury and 10 people as having a past problem. These included the following: stroke, stomach problems, angina, heart attack, oedema, dislocated knee, hip replacement, cerebral palsy, cancer, spine problems, foot injury, epilepsy, chest infection, stoma, hernia, schizophrenia, and asthma.

Expressing pain through language and behaviour

Respondents reported that, of the 22 individuals who used language, 19 (86%) expressed pain using words that would immediately be understandable to someone else, e.g. 'It hurts', 'It's sore.', 'It's painful'. The remaining 3 individuals used non pain specific language e.g. 'Poor (own name). Boo hoo'.

Of the 24 individuals who were reported as expressing pain through their behaviour, in 13 cases (54%) this would also be understandable to someone else. In most cases this related to the person indicating where the pain was or rubbing the area while verbally expressing that it hurt. The remaining 11 people were reported as using idiosyncratic behaviour to express pain, e.g. pulling up a trouser leg, lying down holding a blanket. Of the 5 people who did not use behaviour to express pain, all were reported as expressing that they were in pain verbally in a way that was clear to others, e.g. 'My head is sore.' 'I have a pain in my arm'.

Expressing distress through behaviour and language

Twenty people were reported as using language to express distress. Of these only 6 (30%) used terms that were considered to be clear to a relative stranger, e.g. ‘I am upset because...’ Of those who used more idiosyncratic language, common words and phrases included the use of threatening statements, swearing, and repeating “No”. Only 5 out of the 24 (21%) who were described by carers as expressing distress through their behaviour used indicators that immediately indicated distress e.g., crying.

Table 1 provides details of the language and behaviour which were reported by carers as being used by the individuals with an intellectual disability to express pain and distress, based on their knowledge of the person.

INSERT TABLE 1 ABOUT HERE

Distinction between indicators of pain and distress

In only 3 out 29 cases (10%) were individuals reported as displaying the same behavioural indicators for both pain and distress. This was true for 2 of the 20 (10%) who used language to express pain and distress. For one of the two cases where language was used the carer did not describe any behaviours for either pain or distress, perhaps because the individual concerned was reported to have comparatively good use of language in both domains. In the second case, despite the individual having some use of language, the carer reported no difference between pain and distress words and behaviours. However as the individual clearly communicated distress, i.e. agitation and anxiety, suffering was clearly conveyed. For the individual

who did not use language, the carer relied on their own knowledge of the person they supported, with cues from facial expression.

Level of intellectual disability and expressions of pain and distress

Table 2 provides a summary of the number and percentage of individuals who were reported as using behaviour and language to express pain and distress according to level of intellectual disability and whether it was idiosyncratic or not. Again, language was categorised as being idiosyncratic if the communicative intent would not be apparent to someone who did not know the person well and if the words used are not commonly recognised as describing pain or distress. Similarly, behaviours were coded as being idiosyncratic if they appeared specific to the individual and did not have a pain- or distress-specific communicative intent that would be clear to a person who was unfamiliar with the individual. In contrast, non-idiosyncratic language and behaviour was that which had a commonly understood communicative intent which would be immediately apparent to someone who was unfamiliar with the person with an intellectual disability. Examples of each category are shown in table 1.

Due to the small numbers in some categories it was not valid to analyse this data statistically, however, a number of patterns were indicated. Firstly, table 2 suggests that the majority of individuals who are reported as using language to express pain, do so using language that is recognisable to others, at all levels of intellectual disability. The level of intellectual disability, does, however, appear to impact both on whether behaviour was used to express pain and the type of behaviour used. Those individuals who were more intellectually disabled were more likely to be reported as using behaviour to communicate pain and more likely to use behaviour that was idiosyncratic.

In relation to communicating distress, the majority of those who were reported as using behaviour to communicate distress did so in ways that were individual to them, using behaviours that did not have an easily discernible communicative intent, irrespective of level of intellectual disability. A similar pattern was found for the language that was used to communicate distress, with the exception of people with a mild intellectual disability, the majority of whom used language that had shared meaning.

INSERT TABLE 2 ABOUT HERE

DISCUSSION

The recognition of pain, and its effective management, are concerns in the care of people with an intellectual disability. To date the pain literature in relation to this group has mainly focused on behavioural indicators of pain and distress, rather than the language which is regularly used to express such concepts. This study has provided a preliminary investigation into the pain vocabulary which is reported by

carers as being used by people with an intellectual disability. It has demonstrated that the majority of people in the study sample who have verbal communication, were described as using pain language consistently and in ways that would be understandable to someone who did not know them well. This was true across all ability levels, with the exception of people with a profound intellectual disability, most of whom did not use either verbal communication or specific pain behaviours.

The results of this study are consistent with those found by Beacroft and Dodd (2011), in that the reported language used was not detailed in terms of the type of pain e.g. ‘throbbing’ ‘stabbing’. However, such terms are secondary pain language (Fabrega & Tyma 1976) and are metaphorical uses conveying aspects of activity, deformation and violence (Smith 1998). As such, it remains for further investigation to explore the place and understanding of this level of pain language for people with an intellectual disability. All the pain terms the current study elicited are primary terms, e.g. hurt, sore (Fabrega & Tyma, 1976), suggesting that particular features or qualities of pain experience may not be readily communicated. Nevertheless, the fact that for many individuals pain language was used in conjunction with behaviour to indicate the location of the pain, means that this can begin to inform the diagnostic and treatment process in order to try and alleviate the pain (Bromley et al. 1998).

The research by Bromley et al. (1998) also indicated that, with training and practice, people with an intellectual disability could make quite sophisticated and reliable judgements about location and intensity of pain. It may be that similar input could help build on the language vocabulary that people with an intellectual disability already use to describe their pain, in order to elicit more detailed and diagnostically

rich descriptions. Early work by Dodd (1999) with five men and five women with an intellectual disability also indicated that understanding of body functions, appreciation of the process of GP consultation, and the use of visual aids can support and help develop communication skills. Ruddick and Oliver (2005) have also developed a self report measure of health status for people with an intellectual disability.

The present study found that all of those who had language skills attempted to verbally communicate that they were in pain to their carer. This contrasts with the results of the recent study by Beacroft and Dodd (2011) in which worryingly, it was found that only a third of participants with an intellectual disability said they would share that they were in pain with another person. The reason for this discrepancy is unclear, but may be due to the fact that the present study was based on carer reports. Carers of those people who do not communicate about their pain may have been less likely to participate, as they may not have seen the research as relevant to the person they support.

The study also examined the language which people with an intellectual disability used to express distress and, in general, those people who were reported as using language to communicate pain also tended to do so to communicate distress. The language in the latter case was, however, much more likely to be idiosyncratic, with the meaning only being apparent to someone who knew the person well.

The results also suggested some differences in the way that individuals communicate distress and pain, which was also influenced by level of intellectual disability. While the sample size was insufficient to allow for statistical analysis of the data, broad

patterns were indicated. The majority of people who were verbal were reported as using language to express pain that had a shared meaning, irrespective of level of intellectual disability. However, those with greater degrees of intellectual disability were more likely to be reported as using pain behaviours without language, and these behaviours were reported as idiosyncratic. In relation to communicating distress, those who had greater levels of intellectual disability were also more likely to be reported as using behaviour to communicate distress, and again this behaviour was more likely to be personal to the individual and without a clear, shared symbolic meaning. Similarly, with the exception of those with a mild intellectual disability, the language that was reported as being used to communicate distress was less likely to have a shared meaning.

These results suggest that overall, language and behaviours associated with distress are more likely to need active interpretation than language and behaviours communicating pain. This is perhaps understandable, given that individuals are less likely to have a shared concept of 'distress' (Regnard et al. 2007), as it can encompass a wide range of emotions e.g. upset, anger, confusion and have a wide range of causes (Symons et al. 2008). Furthermore, physical 'pain' may provide a clearer focus, thereby attracting more specifically acquired basic vocabulary and behaviours than more nebulous experiences of 'distress'. Even 'basic' emotion terms such as *fear* and *anger* are open to multiple understandings depending on internal state and social context (Russell, 2003), as well as being intricately connected to level of language ability (Pons, Lawson et al., 2003). The study also supported the distinction between 'distress' and 'pain' (Regnard et al. 2007) in that only 10% of individuals were reported as using the same behavioural indicators and language to express both

concepts. It does, however, suggest that caution should be exercised in assuming that assessments of distress based on behavioural indicators will identify pain related distress, as the behavioural indicators, at least in the present study, seemed rarely to overlap. For those with a profound intellectual disability work such as that by Herr et al. (2006) on pain assessment in those who cannot communicate verbally, remains the first recourse when pain is suspected.

The study does have a number of limitations. While the response rate was in line with other postal surveys, overall numbers were still small, which limits the extent to which the results can be generalised. This also meant that statistical analysis of the data was not possible. In addition, the results were based on subjective staff reports of the language and behaviour used by the people they supported. This methodology was chosen for the purpose of the study, in that the aim was to evaluate the extent to which people, at all levels of intellectual ability, used language and behaviours that others could understand to indicate pain and distress. However, it should be noted that carer interpretations of the language and behaviour used to express pain and distress, while based on knowledge of supporting the individual with a learning disability, were subjective and it is important that future research explores the concepts in more detail directly with people with an intellectual disability. A further potential limitation related to the inclusion criterion which specified that the respondents must have supported the individual with an intellectual disability for a minimum of one month. This time period was chosen based on previous research that people with an intellectual disability commonly and frequently experience pain (Breau et al. 2003, 2007), in order to ensure that carers were not excluded who would be able to provide information about the language and behaviour used by those they supported. This did,

however, raise the possibility that differences would exist between the reports of carers who had been in a support role for long periods, compared with those who were newer in the role, due to the former having greater knowledge about the person they supported. In reality, only one respondent had been a carer for less than 4 months, and she was able to report on the language and behaviour used when the person she supported was in pain.

Conclusion and implications for practice

In summary, the present study found that the vast majority of people with an intellectual disability who had verbal communication, used language to express pain that would have been immediately understandable to someone who did not know them well. The information about pain was often basic, however, it was frequently used in conjunction with behavioural indicators of the location of the pain. This suggests many people with an intellectual disability can be active participants in describing their experience of pain and that nursing staff should attempt to obtain this information directly from the individual during the diagnostic process, as well as obtaining carer accounts. In contrast, the language and behaviour used to express distress was much more idiosyncratic and relied on someone who knew the person well to interpret the meaning. The study supports the conceptual distinction of physical pain and distress, with distress being understood as applying to a broader, less focused range of socially contextualised emotional experience. This suggests that pain assessments that do not differentiate between the two concepts may have less utility when used with people with an intellectual disability. In addition, nursing staff need to be mindful of the distinction between the two concepts and should not react to signs of distress as being indicative of pain, for example by giving medication,

without carrying out further assessment to ensure that pain is, in fact the cause of the distress. The findings support the value of work done towards staff training reported by Mackey and Dodd (2011), which sought to improve staff understanding, recognition of, and responses to pain in people with an intellectual disability. Taken together with other work in this area reported here, it is clear that the time is now ripe for more thorough investigation into the abilities of people with an intellectual disability to express their pain and distress, and to further facilitate their involvement as active partners in communicating about their health issues.

Study Design (KM & MS)

Data Collection and Analysis (KM & AM-P)

Manuscript Preparation (KM & MS)

Conflicts of interest: None

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Table 1: Examples of behavioural and verbal indicators of pain and distress displayed by individuals with an intellectual disability, as reported by carers.

	Behaviour		Language	
	<i>Recognisable to others</i>	<i>Idiosyncratic</i>	<i>Recognisable to others</i>	<i>Idiosyncratic</i>
<i>Pain</i>	‘Rubs stomach area’ (while saying ‘Am sore’) ‘Puts hand on chest (while saying ‘I’m no feeling well’) ‘Points to where is sore (while saying ‘sore’) ‘Touches and points’ (while saying ‘sore’) ‘Hold the part that is in pain’ (while saying ‘Oh, sore.’)	‘Pulling up trouser leg.’ Raises hand to chest, pointing with full hand ‘Shakes arms.’ ‘Stops in middle of task.’ ‘Makes high pitched noise’ ‘lying on sofa with blanket, cuddling into pillow.’	‘I feel unwell’ ‘I’ve a sore foot, leg etc’ ‘Sore’ ‘I’ve got a sore head.’ ‘Sick’ ‘No well’	‘Mumbles in her own language.’ ‘Not to say (can be any word).’ ‘Poor (name). Boo hoo’
<i>Distress</i>	‘Cry’ ‘Throw things’ ‘Shouts’ ‘Cry or shout.’ ‘Cries, shouts, swears’	‘Make himself sick’ ‘Turns around 360 degree circle’ ‘Taps head’ ‘Won’t eat’ ‘Tries to self harm.’ ‘Spit, scratch, roll her thumbs.’ ‘Bites her fist, turns her head	‘I’m stressed, sad, upset’ ‘I got a fright there.’ ‘Oh, (name of carer) there is something wrong with me. Help me.’ ‘Not putting up with it’ ‘That upset me.’	‘polis, 999’ ‘He will go back in time and tell you what person (he is afraid of) has done to him’ ‘I scratch your eyes out.’ ‘You no get cake.’ ‘Her’ (while pointing finger, but no-one is there.)

		<p>away from you.'</p> <p>'Waves arms about.'</p> <p>'Rock vigorously in chair.'</p> <p>'Tries to bite herself or support worker.'</p>		<p>'Makes deep growling noise.'</p>
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Table 2: Type of behavioural and verbal indicators of pain and distress according to level of intellectual disability.

	Pain				Distress			
	Behaviour		Language		Behaviour		Language	
	Idiosyncratic		Idiosyncratic		Idiosyncratic		Idiosyncratic	
	Yes	No	Yes	No	Yes	No	Yes	No
Level of Intellectual Disability (no.)								
Mild (4)	0	1	0	4	3	0	1	3
Moderate (6)	1	4	1	5	4	2	3	3
Severe (8)	2	6	1	7	5	1	7	0
Profound (6)	5	0	0	1	3	1	1	0
Unknown (5)	3	2	1	2	4	1	2	0
Total	11	13	3	19	19	5	14	6

Appendix 1: Pain Questionnaire used in the present study

Identifying Pain and Distress in People with an Intellectual Disability

We would like to find out more about the ways in which people with an intellectual disability let others know that they are in pain or distressed. We would be grateful if you could complete the questions below in relation to the person you support and return the questionnaire to me in the stamped, addressed envelope provided. Any information you give will be stored securely and used on an anonymous basis.

Demographic Information

About you

Gender: Male/Female

Age:

Ethnic Origin:

known):

About the person you support

Gender: Male/Female

Age:

Ethnic Origin:

Level of Intellectual Disability (if

Mild/Moderate/Severe/Profound

1. What is your relationship to the person you support?

2. How long have you known the person you support?

3. Does the person you support have:

a. Any *current* medical problems/injuries: No/Yes (If yes, please provide brief details)

b. Any *past* medical problems/injuries: No/Yes (If yes, please provide brief details):

4. How does the person you support communicate that he/she is in <i>pain</i>?	
What does he/she do?	What does he/she say? (please list any specific words or phrases that are used)

5. How does the person you support communicate that he/she is *distressed* (e.g. upset/afraid/worried) ?

What does he/she do?

What does he/she say? (please list any specific words or phrases that are used)

Thank you for your help. Please return the questionnaire in the stamped addressed envelope provided.